1.0 Introduction
The purpose of this paper is to provide a summary of the current evidence relating to the most commonly used interventions for children/young people with an Autistic Spectrum Disorder (ASD). It has been written to inform the Local Authority about evidence-based practice in order to help the decision-making process for children and young people within Buckinghamshire. It may also be used by parents/carers and professionals who, when considering the support needed for a child or young people with ASD, may feel confident that their preferred intervention is appropriate. An intervention would be considered as appropriate if it is effective, resource efficient and evidence-based. The purpose of seeking an evidence-based intervention is to ensure that any investment made, albeit a time, family or financial commitment, is the best use of that resource.

2.0 What are the main interventions for individuals with ASD?
The National Autistic Society (NAS) estimates that approximately 700,000 people in the UK have autism; this equates to about 1.1% of the population (NAS website, 2013). There is no cure for autism as it is a life-long developmental condition; there is also no definitive evidence as to what causes the condition. This means that there are many different viewpoints about the best way to help, or work with people who have ASD.

There are many claims of a ‘cure’ for autism, all of which are without foundation. However, there are interventions that can help some of the core features of autism, some of the symptoms, behaviours and problems commonly associated with autism, and support families and carers. There is also evidence for treatment strategies to reduce behaviour that challenges.

NICE Guidelines 2013

A large number of interventions and activities are currently available in the UK to help the symptoms and behaviours associated with ASD. These are based on different understandings of the condition and rely on a wide range of therapeutic approaches; all however aim to make a positive difference for children and young people involved.

Research into the most commonly used interventions for ASD has been conducted by Research Autism, which is a UK charity associated with both the Autism Research Centre at the University of Cambridge and the National...
Autistic Society. According to information from their website, their organisation is; “...the only UK charity that is exclusively dedicated to research into interventions in autism”. The interventions considered by Research Autism embrace techniques that are underpinned by a variety of philosophies and approaches, including those from the fields of medicine, education and complementary therapies.

In an A to Z list of interventions, treatments and therapies on the Research Autism website, a total of 1085 approaches have been recorded and the charity have evaluated 130 of those used widely in the UK. Out of these 130, the interventions appear to fall into eight distinct categories; these are reported as follows:
• Modified Diets (eg gluten-free, casein-free diet)
• Behavioural Approaches (eg The Lovaas Method)
• Medication (eg Anti-Psychotics)
• Augmentative Communication (eg Picture Exchange Communication System, or PECS)
• Sensory Integration Techniques
• Specialist Education (eg Schools for children with autism)
• Speech and Language Therapy
(From the ‘Research Autism’ website, 2013)

Research Autism report that robust and reliable research into the effectiveness of interventions for people with autism is limited and this can make it hard to identify the right course of action for a particular child or young person. They emphasise that it is important to be cautious when considering the reported effectiveness of a particular intervention because some therapies offer unsustainable or unrealistic benefits. Moreover, some interventions can even prove to be damaging to the child or young person; for example the use of antipsychotic medication with children who have ASD can be considered as controversial because these particular drugs do not have a UK marketing authorisation for this group of patients (National Institute for Health and Clinical Excellence (NICE) Guidelines, 2013).

“Most interventions appear to produce benefits of some kind, otherwise people wouldn’t use them. Unfortunately in some cases these apparent benefits are short-term, insignificant or illusory. And any benefits may be outweighed by the financial and emotional costs of the intervention, or the dangers inherent in some therapies”.

(Research Autism website, 2013)

Recommendations from NICE included the use of psychosocial interventions delivered by trained professionals in order to target the core features of autism and the presence of behaviour that challenges. Pharmacological interventions for behaviour that challenges were only considered to be appropriate when psychosocial or other interventions were not found to be
effective. It was recommended that the use of these medications should be closely controlled and monitored.

“The management and support of children and young people on the autism spectrum”

National Institute for Health and Care Excellence (NICE, 2013)

Key priorities for implementation
1. Access to health and social care services
2. Knowledge and competence of health and social care professionals
3. Making adjustments to the social and physical environment and processes of care
4. Psychosocial interventions
5. Anticipating and preventing behaviour that challenges
6. Psychosocial interventions for behaviour that challenges
7. Pharmacological interventions for behaviour that challenges
8. Families and carers
9. Transition to adult services

It is evident that further research is needed, not only regarding the use of medication for children with ASD but also more widely in relation to interventions that provide the best support and ameliorate the symptoms of ASD most effectively.

3.0 Comparing interventions for individuals with ASD

3.1 Challenges of comparing interventions
Analysing the effectiveness of interventions for children and young people with ASD is a complex process. This is not only because of the large number of therapies and approaches that are available but because, as previously stated, there is little high-quality research available to help make these comparisons. Research studies may contain problems with the way that the research has been designed, the length of time that the study has run for, or in distinguishing whether any improvements made were due purely to the intervention, or whether they occurred because of other factors (Beresford et al, 2012). All of these issues may mean that the study was unscientific and that conclusions cannot be drawn from the information that was gathered.

Comparing interventions can also be difficult because every person with ASD is unique and this can make it difficult to match the results of one study to
another. These individual differences may be considerable; not only is autism a continuum upon which people may experience associated difficulties to a greater or lesser extent, but the NICE Guidelines regarding the diagnosis of autism report that around 70% of individuals with ASD have other psychiatric difficulties of such significance that they meet the diagnostic criteria for an alternative diagnosis. Issues of this type mean that an intervention that has been effective for one person may not meet the needs of someone else, even when their profiles appear to be similar.

Many studies only focus upon one aspect of the individual’s autism, which can also make it difficult to compare the results of different interventions. For example Beresford et al (2012) at York University reviewed the success of parenting programmes that aim to improve the sleep and behaviour of individuals with ASD; however these results cannot help to understand other aspects of the individual’s autism, such as their social development. The specificity of this study means that there is a limited amount of research to compare it with in order to identify whether the results achieved may be supported by other researchers.

Finally it can be difficult to define what is meant by success in an intervention; for example a particular approach may help a child to develop more complex speech patterns, but this may result in a deterioration in other areas, such as increased anxiety or the acquisition of additional obsessional behaviours. Would this intervention be considered successful because of the improvements made, or unsuccessful due to the areas of deterioration? This type of debate is one reason why research results can be difficult to measure and interpret.

Research Autism state that even some scientific studies may contain errors and this means that the information that has been gathered will not be accurate or show true results from the intervention. The charity provide an excellent and comprehensive overview as to why research studies into autism may contain faults, including those relating to the purpose of the research, the participants involved, and the outcomes and measures used (see ‘Why Some Autism Research Studies are Flawed’, Research Autism website 2013).

Evidence from the literature suggests that the comparing of interventions for ASD presents a number of challenges due to the numbers of interventions involved, methodological issues and the lack of high-quality research that is currently available. Progress in this area is a dynamic process and therefore organisations such as Research Autism which are currently undertaking this
challenge should be considered the centres of excellence in comparing and reporting upon the effectiveness of ASD interventions in a rigorous and scientific way.

3.2 Comparing the resources required for different interventions
Research indicates it can also be difficult to compare the amount of resources required for an intervention because this will depend upon a number of factors including:

- How much time the approach takes
- The duration of the intervention
- How manageable the intervention is in ‘real life’ terms

For example, when Beresford (2012) considered the impact of four parenting interventions for children with ASD they superficially appeared to be similar in content, however the cost of delivering each programme was found to range from £3410 to £8325, which represents a wide variation in price. These differences resulted from the number of sessions that the parents were asked to attend, the size of the parent groups involved and the number of professionals who were required to attend the sessions. The outcomes of these programmes also revealed considerable differences, so whilst the commissioners of services for the Local Authority have a responsibility to ensure that any intervention invested in provides good value for money, caution should be taken against making comparisons between interventions on a purely financial basis.

Costs of an intervention for an individual will also show variation and will be affected by the individual differences of the person with ASD, including whether they have learning difficulties, whether they are considered as having high-functioning or low-functioning autism and whether they require the support of specialist services, such as the Occupational Therapy Service. Knapp et al (2009) estimated that it costs £3.1 million pounds to support an individual with ASD throughout their lifetime if they have high functioning ASD and £4.6 million if the individual is considered to have low-functioning autism. One of the costs incurred related to the degree of support that the individual required at school. National data indicates that whilst approximately 70% of children with ASD attend mainstream schools (DfE, 2009), the costs for the remaining 30% in special schools may vary dramatically, depending on the nature of support that the individual requires. Special school charges will depend on the number of weeks per year in which the child or young person is placed at the school and the specific services that is offered by the provision. Whilst Knapp et al, using figures from 2005-6, estimated that special education for a child of any age with high-functioning autism would be expected to cost approximately £12000 per year, this increased to almost £28000 for a secondary school aged pupil with low-functioning ASD. This may be considered a relatively modest amount when some special schools charge in excess of £100 000 per year, especially if they provide respite or residential care for the child or young person.
Residential provision may be sought when families have difficulties in managing the behaviours of a young person with ASD or as a result of family breakdown. Support for families is an area that has been identified as being of particular importance in the research literature. Bromley et al (2004) reported that the stresses upon families who have a child with ASD are greater than those placed on the families of children who have other developmental difficulties, whilst Hartley et al (2010) reported that families who support an individual with autism are 60% more likely to divorce than those who are not under the same pressures. Support for families and carers was also identified as one of 9 priorities in the management and support of children and young people on the autistic spectrum contained within the NICE guidelines (NICE, 2013). A unified approach, using expertise from Health, Education and Social Care to support the child and young person within their domestic and educational environments therefore appears to offer best practice in meeting the needs of the individual, rather than a intervention viewed in isolation.

4.0 In search of evidence-based interventions

In considering the challenges involved in providing a summary of the current evidence relating to interventions for individuals with ASD for the Local Authority, the literature indicates that the most rigorous and robust information available is published on the Research Autism website. This has the benefit of being updated regularly, with access to peer-reviewed journals and cutting edge research to provide the most comprehensive review of the most widely used UK interventions for ASD.

Information from the website has therefore been replicated for this paper (see Appendix 1); this has been slightly adapted in its format and wording, but the content remains unaltered. It should be stated that whilst this is current as of October 2013, the information is likely to change and therefore it is recommended that future information is obtained directly from the website. The symbols used by Research Autism have also been used in Appendix One, in order to avoid confusion when looking between the two contexts.

In interpreting the information, it is important to state that Research Autism report; "Each intervention is rated according to the amount and quality of scientific evidence which has been published in peer-reviewed journals that supports or does not support the effectiveness of that intervention. We also provide information on whether each intervention is considered to be hazardous" (Research Autism website, 2013)

It is important to reiterate the information from Research Autism’s website that the ratings do not mean that the charity are recommending particular interventions for individual people, rather they are able to provide information about those programmes that have an evidence based from current research. It is also important to state that a number of interventions are reported as ‘ungraded’ because there has been no opportunity for rating the intervention; this should not therefore be interpreted as a negative rating. Studies regarded as having ‘limited positive evidence’ may do so because of the lack of high-
quality research evidence in the area, rather than due to poor outcomes in the studies that have been conducted.

Studies displaying the most effective results from published, peer-reviewed journals include the following:
- Cognitive Behavioural Therapy
- Early Intensive Behavioural Therapy
- Melatonin
- Music Therapy
- Olanzapine
- PECS
- Pivotal Response Training
- Risperidone

Positive evidence has also been found for the following interventions:
- Gluten free, Casein Free diet
- Incidental Teaching
- Milieu Training
- Social Stories
- TEACCH
- Video Modelling (for example Video Interaction Guidance)
- Visual Schedules

The appropriateness of these interventions for an individual should be considered on a case-by-case basis, and should be informed through discussions between parents/carers, professionals working with the child/young person and with the young person themselves using a patient-centred approach in accordance with the NICE Guidelines (2013). As stated previously, a unified approach will always offer the best practice in meeting the needs of the child or young person.

5.0 Summary
A request was made for a summary of the current evidence relating to the most commonly used interventions for individuals who have an Autistic Spectrum Disorder (ASD). This was to inform the Local Authority about evidence based practice in order to help the decision-making process for children and young people within Buckinghamshire. It was anticipated that the document might also support both parents/carers and professionals when considering which approach might be most appropriate when supporting a child or young people with ASD.

A review of the literature revealed that a large number of interventions are currently available and widely used in the UK, and these reflect underlying philosophies and beliefs about the condition. Whilst they all aim to make a positive difference for children and young people, some have been identified as being more effective than others, and some are controversial or even harmful.
Research into the most commonly used interventions for ASD has been conducted by the UK charity Research Autism, who are in the process of investigating 130 interventions that fall into eight distinct categories. Robust evidence is limited, and there are many challenges in comparing the effectiveness and resources required to deliver an intervention. Having considered the evidence available, it became evident that the most robust information was available on the Research Autism website, and this was replicated, albeit with minor adaptations, for the purposes of this paper.

Whilst Research Autism do not make recommendations in using a particular approach for a particular individual, the information that they provide about the research available in this area is invaluable. Eight interventions were identified that displayed the most effective results from peer-reviewed journals, with a further seven also showing a more limited amount of positive evidence.

It was concluded that any intervention planned for an individual should be considered on an individual basis, and should be informed through discussions between parents/carers, professionals working with the child/young person and with the young person themselves using a patient-centred approach in accordance with the NICE Guidelines (2013).
6.0 References


Research Autism website, 2013
Why Some Autism Research Studies are Flawed http://researchautism.net/pages/autism_treatments_therapies_interventions/autism_treatment_introduction